Recovery in My Lens: A Study on Stroke Vlogs

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Abstract

Stroke is a chronic condition and a leading cause of disability. After hospital discharge, patients need to transition into home-based rehabilitation, a long and distressful process. However, they are often ill-prepared to manage recovery at home; and many are socially isolated. There is a growing number of stroke patients who utilize social media platforms, YouTube in particular, to publish video blogs (vlogs) to make their stories heard and to share their rehabilitation experience. In this study, we analyzed 246 such YouTube vlogs to better understand this new form of patient story-telling and its value to vloggers, viewers, as well as healthcare professionals. We found that vlogging helps stroke patients overcome physical and speech constraints to self-journal, and to connect with other people online. Based on these findings, we discuss how future health systems may leverage vlogs to design self-tracking technologies, to generate patient health data, and to offer patient-centered education.

Introduction

Stroke is a type of brain injury and a leading cause of disability[1]. People who survive a stroke often suffer from weakness or paralysis on one side of the body, communication disorders, and deficits in memory, thinking, and attention. The recovery process usually involves treatment and rehabilitation[2]. Treatment begins with acute care in a hospital, which aims to help patients survive, prevent another stroke, and treat other medical problems. Rehabilitation usually begins during the acute stage and aims to help patients maintain abilities and regain lost abilities. Over the months following a stroke, most patients show spontaneous recovery of behavioral deficits that is generally incomplete. Once a patient returns to his/her home environment, a range of challenges are encountered, e.g., continuous access to professional therapies and managing chronic conditions, issues made all them more complex due to patient functional limitations and social isolation.

To address these challenges, researchers have investigated and designed novel information technologies to help stroke patients better manage their recovery in their homes. Examples include robotics to automate therapeutic exercises, virtual reality and games to provide engaging therapy experience, sensors to detect movement, and telemedicine to deliver therapies via telecommunication[3]. While these technologies are shown to be promising in enhancing patient outcomes, how to enable patients to adopt new technologies remain understudied.

Meanwhile, social media has emerged as a platform for patients to receive informal health education and to connect with other patients as well as health professionals[4]. Among them, video blogs (**vlogs**) have been found to be used by patients to document their progress, share their experiences, and form online health communities. However, little research has studied how vlogs might help patients manage their health outside the hospital environment. The purpose of this research is to investigate *how can medical work be improved based on patient experiences expressed via the vlogs and via viewer-creator interactions*. More specifically, we aim to answer the following research questions (RQs):

- *RQ1: What motivates patients to post video blogs (vlogs)?*
- *RQ2: How and what content are created from vlogs?*
- *RQ3: What is the value of the vlogs to the viewers?*

Background

Online videos have been widely studied in the health and medical informatics field primarily as a source for health education[5], information dissemination[6], and social support[7]. Tackett et al.[5] analyzed 189 videos from one year of YouTube analytics data on a medical education-focused channel and concluded that medical education content on YouTube can immediately and consistently reach a global viewership[5]. In a scoping review by Farkas et al., online educational videos on pediatric needle pain management were evaluated as current, relevant, created by a trustworthy source (i.e., authority), and with relevant purpose[8]. A systematic review of health information on YouTube conducted

by Madathil et al.[6] revealed that public service announcements from organizations, documentaries, and TV shows, and user-generated anecdotal content in which users discuss their perspectives and their experiences were the most commonly found sources. In addition, misleading information is found on YouTube, and the probability of healthcare consumers encountering such material during the information-seeking process is high. Besides educational videos from an authority or healthcare professionals, YouTube health videos are also uploaded by patients. For example, in the setting of health videos for surgery in Crohn's disease[9], among the various sources, videos from patients received significantly more "likes" than videos from hospital associations. Particularly, videos with the theme of experience of disease were most liked by patients, suggesting the themes are important to patients.

In particular, video blogs (vlogs) have become a popular form for patients to share their experiences, stories, and knowledge in the form of online videos with the general public[11]. It can be challenging to engage patients in their own care, and the unique attributes of vlogs overcome some of the barriers to engagement such as high treatment burden and a lack of the sense of community. By studying 72 vlogs of users diagnosed with HIV, diabetes, and cancer, researchers[11,12] identified that vlogs support teaching, personal journals, self-documentaries with nonverbal cues, connecting with audience, engaging other actors, and integrating context filming. These authors also found that vlogs help patients establish rapport with viewers. In addition, vlogs were used for patient education, disease modification, disease management, and diagnosis. From a recent case study of The Frey Life, the vlogs of a patient with cystic fibrosis, Lee et al. found that vlogs can be used as a tool to provide patient perspective and enhance patient engagement through establishing a sense of community[13].

Despite the emerging popularity of vlogs in health informatics, there is a lack of study on vlogs for patients with stroke. We posit that videos might be serve as an important medium for stroke patients. This is because as mentioned earlier, stroke could impact patients at many levels, including physical, speech, and cognitive capabilities, and detecting, diagnosing, and recovering from stroke involves visual, acoustic, and motion cues from patients. A key work is a study by Gupta et al.[14], which investigated the accuracy and adequacy of the information provided on YouTube regarding stroke. They found that YouTube provides a good and reliable source to learn the signs and symptoms of stroke but includes insufficient information about treatment, risk factors, and prevention[14]. Another example of using visual cues was demonstrated in a case study of a stroke patient, whose Facebook photos facilitated neurologists to determine the timing of facial neurological signs[15]. Despite the copious research in online health videos, little attention has been paid to how patient-generated stroke vlogs might be helpful for stroke patients who post and the audience who view the videos.

Methods

In order to study vlogs from patients with stroke, we first searched on YouTube, identified a sample of videos and then conducted content analysis on videos and comments. The methods used in this study were selected based on a systematic review of methods for studying consumer health YouTube videos[4]. Since stroke recovery is a long process that spans from acute stage to chronic stage, it is therefore valuable to investigate any temporal patterns and rich context of each user. Therefore, we decided to search videos in the unit of individual vloggers. The Institutional Review Board at UC Irvine determined that this project does not require review for human subjects research.

Data Collection. To identify relevant vloggers, the first two authors entered the search terms (stroke diary, stroke recovery, stroke rehabilitation) in varying combination into a YouTube search window. To decide on a set of vloggers for analysis, we adopted a combination of videos from the search list and snowball[4] – as video clips were viewed online, we adopted additional recommended by YouTube[16]. The results were screened with the following criteria: 1) vlogger should be a stroke patient, not a caregiver, healthcare professional, organization, association, or industry; 2) the video from selected vloggers should be about stroke experiences; videos that are off topic or re-posted from other sources are excluded; 3) the video should be in English. The search was discontinued when we identified 15 eligible vloggers, who together had 1,644 videos, the number of which already exceeded the maximum number in the literature[4]. Among the studied vloggers, one subject started the daily video diary since 2014 and is continuing at the time of our study, which produces 1,421 videos. To avoid analysis and findings being dominant by one vlogger, we randomly selected one vlog in each month for this user. For the other 14 subjects, all their vlogs were included for analysis. In this way, we selected 246 videos from 15 vloggers.

We then collected online accompanying data about the vloggers and their videos. The data collected from each vlogger include the web page URL and the number of subscribers, gender of vlogger as inferred from the videos; the data collected from each video include its URL, descriptions of the video, clip length, number of views, number of likes, number of comments, and comments, upload date, and the description of the video.

*Data Analysis***.** We first performed descriptive analyses for the vloggers and analyzed the content of videos as well as their comments. For the videos, we performed a content analysis, which was the primary technique employed by researchers to analyze the characteristics and themes of the videos[6] with the aim to answer the following two questions: 1) why they vlog, and 2) what topics are covered. The first two authors randomly reviewed two videos of each vlogger together and iteratively developed a codebook. We then iteratively coded all the videos using the developed codes and recording the codes in two separate Spreadsheets. After reviewing and discussing the coding results, we manually transcribed representative video clips that contain relevant contextual information with the assistance of the YouTube Transcript function. For the comments, we performed a thematic analysis to identify themes of comments from the viewers and posters.

Table 1. Descriptive data of individual vloggers and videos. Note: we used pseudonyms to protect user privacy.

Name	Gender	First vlog	Latest vlog	Duration (months)	Subscribers (N)	Vlogs (N)	Avg clip length (mm:ss)	Avg views (N)	Avg likes (N)	Avg comments (N)
Lachlan	M	01/31/17	02/02/17	1	0	9	0:55	6	0	0
Wilbert	M	06/10/09	05/08/10	12	11	4	1:02	516	1	0
Robert	M	10/05/16	12/18/16	2	3	20	4:11	8	0	0
Amy	F	01/09/17	01/13/17	1	11	6	10:28	146	2	1
Hanna	F	07/30/15	08/06/15	1	18	4	8:36	427	3	1
Jasmin	F	02/05/13	06/26/16	36	31	6	4:42	121	1	1
Jim	M	09/26/10	07/28/11	8	4	5	3:11	42	0	0
John	M	06/07/10	12/26/11	18	920	6	8:46	36964	106	11
Tracy	F	08/01/15	12/16/15	4	308	13	1:28	6055	15	4
Ingrid	F	01/31/13	10/28/16	36	123	17	3:08	2531	8	1
Phil	M	03/12/12	05/18/13	48	487	9	6:32	12038	54	8
Miller	M	02/16/16	12/13/17	24	674	8	5:56	12095	117	31
Sarah	F	09/04/16	06/27/17	8	10	51	7:13	32	0	0
Daniel	M	01/09/12	03/24/17	59	6	67	2:10	8	0	0
Pitz	M	04/27/14	02/20/18	48	323	1421	1:07	136	2	1

Findings

We analyzed 246 videos (total clip length 16:40:52) and 441 comments. Table 1 presents the descriptive data of the selected vloggers. The table shows a wide range of vlogging duration (min=1 month, max=59 months) and frequency of vlogs among each individual and their number of YouTube channel subscribers (min=0, max=920). The average number of views (min=6, max=36,964), likes (min=0, max=117), and comments (min=0, max=31) of each video also varied substantially. We did not analyze the demographics of commenters due to the heterogeneity of commenter population. In the rest of this section, we present findings to address the above research questions.

RQ1: What motivates patients to post video blogs (vlogs)?

The motivation for blogging is mainly mentioned in the first video of each user's vlog series through directly talking in the video or the descriptions of the video. Our subjects revealed the following reasons for video blogging, facilitated by the affordance of YouTube: 1) *videos* as a medium to compensate their physical challenges, 2) *uploading* as a tool to self-document, and 3) *sharing* as a tool to facilitate social interaction.

a) Video as a medium to address physical challenges. In particular, patients used videos to document their progress in relation to their physical limitations. For example, by showing her handwriting in the video, Sarah mentioned that video is more convenient for her than writing or typing because she *"cannot write well."* In addition, video is a suitable medium for patients to record therapeutic exercises that contain rich visual, audio, and motion cues. Various factors are crucial in determining the progress such as range of motion and speed. For speech therapy, pronunciation, speed of speech, and facial expression are crucial in assessing their progress. Video media contains much richer information to document the motion and sound compared to other media such as photos or text.

b) Uploading as a repository to support journaling. Users mentioned that they use videos to document their physical states and recovery progress. As a vlogger who experienced aphasia said in his first video diary:

> *"This is my new voice. I am going to video diary my voice every week to see how much my voice improve. This is week 8 since i took ill. i haven been home just under 2 weeks." -- Wilbert*

Many users record the videos to inspire and motivate themselves in the future, when they feel frustrated or staggered in the recovery. For John, *"the real goal is to film this and in a month or so, maybe when i am feeling i am not making any progress and i can come back to this and hopefully i can see i am much better."*

c) Sharing as a channel to facilitate social interaction. Patients were motivated to share their videos for various purposes: using them as an emotional outlet, keeping family and friends updated, providing informal education. As vloggers mentioned, they frequently experienced isolation, stress, frustration during stroke recovery, and according to one vlogger, Amy, she would "*use this as an outlet to filter."* Users also mentioned that people frequently asked them about their progress and situation thus far, therefore, they recorded the posted the videos on YouTube so that people who cared about them were aware and updated about their situation, and *"also give you a chance to see how i am doing"* – Sarah.

Further, users frequently mentioned the purpose of sharing their recovery experiences, practices, and exercises with patients who encounter similar experiences, e.g., *"show you some exercise i have been doing."* (Phil). In particular, vloggers also share with new stroke patients who might have less knowledge. For Hanna, she used the videos to teach her audience how to detect a stroke:

> *"I want to share this with everybody. Being 40 something, and nothing would put me into hospital for a long time; this stroke took me by surprise. for anyone who needs to see the sign, watch the face, to see if it is numb... I want to keep it educational to look for sign of stroke."*

Through videos, which address the physical constraints and recovery needs for stroke patients, vloggers upload videos to document their recovery journey and shared videos on YouTube to facilitate social interaction.

RQ2: How and what content are created from vlogs?

The videos were mainly presented in the form of narration and demonstration. In **narration**, users tell stories in front of the camera and record them in videos. In **demonstration**, users mainly use "show and tell" to record and express themselves. Among the fifteen users, two of them uploaded exclusively demonstration videos, five only narration videos, and eight adopted a mixed of both. This includes 173 narration videos, 98 demonstration videos, and 25 mixed videos. Through narration or demonstration, users presented the following themes: 1) stroke onset and cause, 2) therapies and treatment, 3) activities of daily living, 4) current progress.

a) Stroke cause and history theme introduces what has happened during patients' cause of stroke and their treatment history since stroke onset. When reflecting the reasons of being caught on stroke, Tracy said that she *"didn't do drugs, didn't smoke, didn't have high cholesterol. Heart was fine. It didn't have any holes in it. The only thing that might cause stroke is birth control."* Stories about stroke onset and treatment history usually appeared as the first video of a user's vlogs and in the form of narration. For example, in John's first video, he said:

> *"I had my stroke on April 21st. … three weeks of acute rehab at the hospital, was five days a week, three hours a day. Since then it has been outpatient rehab at the outpatient center. That was two or three times a week, divided by partially the arm and the leg… my whole left side was paralyzed and couldn't move."*

Similar to John, users talked about their stroke history as a way to record what had happened and laid a background for the video to connect with their audience.

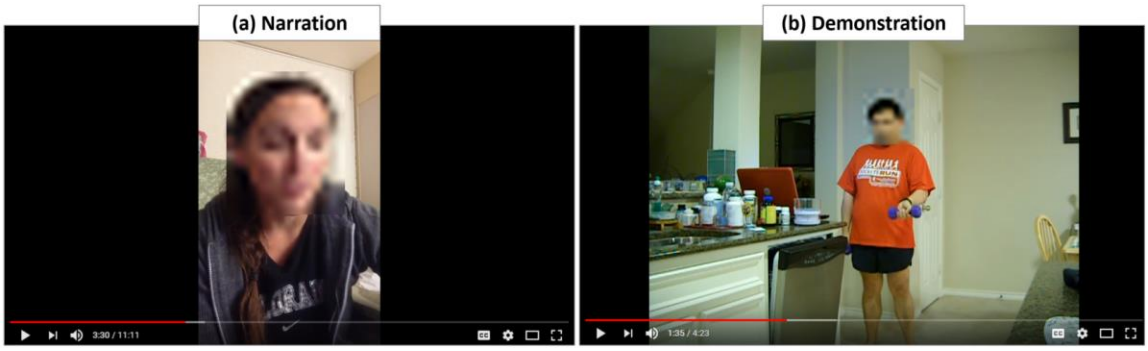

Figure 1. Screenshots of video clips: narration vs. demonstration. Note: users' faces are pixelated to protect privacy.

b) Therapies and exercises are conducted either with therapists or by patients themselves. For therapies conducted by health professionals, videos mainly include the factual information such as the dates and list of exercises and their feedback for the therapies and the recordings of the whole session. For exercises conducted by patients themselves, patients usually demonstrated and recorded the exact movement they performed. For example, Tracy recorded her occupational therapy sessions with the therapist (Figure 2 (a)), and Lachlan uploaded multiple videos of himself working on fine motor skills, arm and wrist strengthening, and shoulder movements (Figure 2 (b)). Patients might also narrate the exercises while recording them. As Phil said in the video:

> *"I am showing how I am progressing and a few exercises I'm doing for physical therapy. As you can see, when I am walking around, I can get around okay. And just to do the therapy, I have a whole list I can go through, and I can start from my head to the bottom basically. …"*

Figure 2. Screenshots of exercise video clips: clinic-based vs. home-based. Note: users' faces are pixelated to protect privacy.

c) Activities of daily living is another main theme presented using narration or demonstration. Patients talked about their roundabout during the day to record them in the videos. Some users talked about their activities of daily living to reflect on the potential association between their activities and the recovery.

> *"Today I had a vendor event. I decided to do it. I got help from some people. It was a very long day for me. Probably not a good idea to do it this soon. I had to be there at 8'olcok this morning, working on setting the table… and then by 8:45 o'clock I was tired…then my mother showed up. Then around noon, I had this wave of exhaustion, absolute exhaustion. I could not hold my head up. …"*

Users also used activities of daily living to record the milestones in their recovery journey. Peter recorded a video demonstrating that he *"got up as usual emptied the dishwasher took the bottles through then got some small logs wife to start the fire tomorrow and some large ones for tonight our friend is coming to set up her-web site this afternoon"*, as is shown as the description of the video.

d) Current progress is narrated or demonstrated in the videos by showing the differences of their current physical states compared with before. As Tracy spoke in her video:

> *"It has been a crazy year. I have done a lot of therapies, I couldn't sit in the hospital room. I couldn't speak. I couldn't move at all. I had a brace on my leg, and a cane. … now I had my speech better. I can carry on*

conversation. I am walking more fluidly. I can walk better up and downstairs. I can make my arm do that (moving her elbow). I couldn't do that three months ago. I'm getting better."

As an additional example, Wilbert recorded his progress in speech in a 2-minute video to show the differences between how he speaks now and how he spoke in his first video diary. As he put in the description of the video: *"This is my 2nd video diary snce (since) my stroke, Can you tell what Ive (I've) said ??? 3 months since my stroke."* He also demonstrated his progress by showing that the less distorted facial movement while he speaks. Similarly, before Ingrid started to sing in the video diary, she said:

> "*First, this is a huge step for me because my voice simply wouldn't move and I couldn't keep tempo at all to begin with, so I'm just being willing to sing publicly is really a big deal and second of all my voice that you will hear today at 18 months is so much better than it was even two or three weeks so I can't even begin to describe certainly better than it was a few months ago."*

Although most videos documented patient improvements, not all the progress is positive. For example, one patient said in his video that "*it now seems to plateau a little bit; and it seems the major improvement is over. So setbacks."*

RQ3: What is the value of the vlogs to the viewers?

We also analyzed the 441 comments made on the videos. Overall, the number of comments on each video varied from 0 to 31. The following themes emerged from the comment analysis.

a) Encouragement. The first type of comments is the encouragement to vloggers. Most comments of this type come from stroke patients who have been through the process or their family members. For example, for a patient based in the US, she received the following comment from a user from Italy:

> *"Hello [patient's name], I'm glad to see you and all the progress you've made. You're beautiful and I wish you much happiness and love you deserve it, and like a Bruce Springsteen song says, No Surrender, Someday girl I do not know when We're gonna get to that place. Where we really want to go and we'll walk in the sun. But till then tramps like us baby we were born to run ... With love I wish you the best Piero from Italy."*

b) Appreciation for Inspiration and Education is the second type of comment. Commenters mostly expressed that the videos have inspired them to continue to make an effort in their recovery.

> *"…you are inspiring. I was starting to lose hope cause my 4th stroke was 4/12 /12 and progress stopped. but your exercises are really helpful as well as your dedication."*

Patients and caregivers who posted the comments reported that they were searching for online videos for rehabilitation exercises since they exhausted their yearly insurance benefits for therapy sessions. The YouTube videos provided them a way to learn and exercise by themselves.

> *"Thank you so much for these videos. I have been searching online and have found nothing like yours. I had mine almost a year ago. My insurance stopped after just one visit to pt (physical therapy). The wait is killing me for my insurance to kick back in. I'm very thankful that this will change my life."*

Some patients also provided feedback after learning from the exercises in the videos.

> "*Thank you so much for making and sharing your PT (physical therapy) exercises for lacunar infarction. I had the same type of stroke in the left brain too. Your exercises for home PT have helped me very much. I am now adding weights and a small amount of yoga. You are inspiring and motivating.*"

Interestingly, some healthcare professionals and medical students also found the videos useful for providing health services for their patients. A commenter, who mentioned him as a "*physiotherapy student*", replied: "*Thanks for showing these! very helpful to see your progress, determined mind-set and the exercises with feedback! :)*"

Overall, most comments showed appreciation in the videos for the inspiration and learning opportunities. For some patients, they also compared the helpfulness of the videos with those from professionals, and commented that "*these videos are more helpful than ones done by pros."* Only a few commenters thought some videos might not be suitable for all stroke patients. As one commenter wrote: "*He suffered only from mild stroke, because 10 weeks after stroke can't do that exercises."*

c) Request for follow-ups and asking questions. Some commenters who were also stroke patients or their caregivers asked if the vlogger had had similar experience with the commenter.

> "*I wanted to know if you have feeling in your right side at all? I had a left hemisphere stroke and I cannot feel anything on my right side but I have pain in the left side of my leg when I walk. It always feels like it is cramping and I have to lean on something for a min."*

Some patients also requested for general advice for stroke recovery. Patients commonly asked follow-up questions after watching the videos: *"Lost my left-hand side 8 months ago. Have regained my left arm, with a little stiffness and aches. My leg unfortunately has not, stiffness aches/ pains persist, walking without aid almost impossible, cannot climb the stairs as normal, only one leg behind the other. Have physio 1time per week since. Would love to see more vids of leg exercises if available. How many times per week did you repeat these?"* Similarly, another patient requested videos about hand exercises, after watching the video about rehab exercises on the lower limbs.

Or they may request that "*keep present video so that we can see how u r at present.*" Some commenters would like to check whether patients who had visible improvement during the acute phase still progress during the chronic phase.

> "*I hope you'll be able to update us on how you are these days in 2014. My friend's stroke happened just at about the same time as yours. She's 22 y.o. now. Your videos are in your post-stroke "acute" recovery phase, and prior to six months post where my understanding is that there is a lot of spontaneous recovery. As it's evident from your videos that you put in a lot of time to your rehab exercises, and I wonder how you are these days in the "chronic" phase. Are you still able to make gains? Can you type? Can you flex back your wrist?..."*

d) Response to questions and requests. Among the fifteen vloggers, only four of them responded to questions on vlogs, with 24 replies to 9 videos. The nine videos are primarily demonstration videos about recovery exercises. The responses are mainly about 1) sharing their experiences, tips and tools, and 2) encouraging other patients.

In answering commenters' questions, vloggers tend to first encouraged them, suggesting that they should *"seek professional help (Doctor and/or Physical Therapists)"* because they "*know your exact needs.*" They then shared their experience and offered suggestions "*if that is not an option*." When describing their situations, vloggers tended to use their abilities in activities of daily living as a reference of their situation instead of medical terms, e.g., *"I can grasp and hold things", "I can zip zippers and slice tomatoes", "I can walk a couple of miles"*. They offered their recovery exercises, such as *"doing shoulder shrugs, curls, wrist curls in an effort to re-wire your brain to your left side, 3 set of 15 repetitions for a couple of hours per day while listening to music. Also putting a rolled-up towel in your left hand and try to squeeze it. Massage your left hand with your right hand. Flex each left finger open to prevent the tendons from tightening up."* In one vlog, when commenters requested that the vlogger shared the Spreadsheet that he used for his exercise, the vlogger emailed the file to everyone who had requested it: *"I am only happy to help… Putting together the spreadsheet helped motivate me to keep up a daily routine plus it gave me much needed practice on the computer. If anyone wants a copy of the Excel Spreadsheet ... just give me your email address via YouTube email."*

Vloggers also encouraged other patients to keep making an effort. As one vlogger said: *"There are no short cuts nor easy methods. Keep trying, then try some more! Don't give up. Let the frustration fuel determination!" "Keep up the Hard Work!! I have been busy at work and am still maintaining my regular workout routine. I have gained back a few pounds because I slacked off on my diet!"* One vlogger also followed up with a commenter asking her "*any updates?*"

Discussion

Prior studies found patients with chronic conditions used vlogs for journaling and connecting with their audience. For example, patients with HIV, diabetes, and cancer vlog to document their physical and emotional status, updates of the treatment, and the experience of struggling with the disease, as well as to facilitate community building[11]. A case study of a cystic fibrosis patient has addressed the roles of vlogs in providing patient perspectives for not only patients but also healthcare professionals[13]. While confirming these findings, we have also discovered ***the unique characteristics of stroke*** that make vlogs particularly valuable. As mentioned earlier, patients with stroke usually suffer from physical and speech deficits. Videos could not only serve as a more convenient medium for them to record their life compared with typing and writing, but also capture rich information about patients' functional states, such as movement, speech, and facial expression. From a social perspective, videos are found to present unique opportunities for vloggers to connect with viewers through building online health communities and seeking social support[11–13]. In addition to prior findings, our study has also indicated that videos with patients demonstrating rehabilitation exercises are perceived as educational materials for viewers. As commenters mentioned, since the rehabilitation exercises were performed by patients with similar experience, they could better relate to the videos compared with those performed by non-patient.

Having confirmed with prior insights on vlogs for other chronic conditions and identified unique characteristics of stroke vlogs, we posit that our findings might also apply to patients with other diseases that involve occupational,

physical, or speech rehabilitation, e.g., traumatic brain injury and Parkinson's disease. We propose opportunities of using vlogs to design self-tracking technologies, to generate patient health data, and to produce educational services for patients with stroke or similar conditions.

Technology: Using vlogs to support self-tracking. Our findings show that vlogs served as a platform for stroke patients to self-track their functional states and the recovery process through demonstration and narration. Prior study has shown the feasibility of using functional outcome instruments to measure and track stroke patients' physical states in clinical and community settings[17]. In our study, however, tracking functional states are conducted in the home settings by patients themselves through narration and demonstration in videos. Patients experiencing aphasia record their speech and facial characteristics involved in speaking; patients facing physical deficits in their hands, arms, and fingers used videos to document their progress through certain activities, such as lifting arms, grabbing, and other fine motor skill exercises; others documented their lower limb recovery through walking, climbing stairs, and standing. Besides video demonstrations, patients also verbally discussed their progress in the vlogs. They considered tracking their functional states and recovery progress as a valuable means to motivate themselves and to document their treatment history.

Self-tracking is an emerging field of study in recent years[18]. Currently, most self-trackers use sensors to quantify users' lifestyles (e.g., physical activities, mood, sleep) as well as clinical indicators (e.g., blood pressure and glucose levels). Self-tracking is considered to be promising for engaging patients in managing their chronic diseases. However, to the best of our knowledge, little work has investigated technological means for stroke patients' self-tracking. While lifestyle measures are closely associated with stroke patients' health, they are designed for the general public with little consideration of the unique needs of stroke patients, as well as other neurological diseases.

Self-tracking for rehabilitation purposes, however, might require different measures to quantify patients' physical states and progress. This is largely because the quantitative measurements of rehabilitation progress in physical functionalities and speech capabilities are commonly designed in the clinical setting. Self-tracking, by nature, emphasizes empowerment of individuals to quantify activities in their daily lives. Their recovery progress, such as movement and speech, is highly visual and acoustic. Therefore, mainstream self-tracking health devices and applications for steps, bodyweight, blood pressure, may not be immediately applicable for tracking recovery. As such, our study reveals opportunities to design and develop self-tracking tools based on videos and audios to help patients monitor their functional improvement. However, we also found that some video clips are low in production qualities, e.g., poorly positioned, blurred, or dark in visual presentation. It is likely that the patients took the videos themselves by placing their smartphone or cameras remotely and auto-recorded the videos; or patients did not have enough physical stability to hold the cameras steadily. Webcams, in combination with voice-driven intelligent personal assistance, might be customized to automatically sense and capture patient motion and speech related to their recovery.

However, self-tracking stroke rehabilitation might need to consider the temporal aspects. As mentioned earlier, recovery could be much faster in the acute phase than in the chronic phase. While visible improvement can motivate patients, slow progress that is hardly observable in a short period of time might demotivate patients, making them perceive their progress has plateaued. Therefore, when designing self-tracking tools for rehabilitation purposes, it is crucial to consider the stage of stroke and its relationship to stroke recovery speed. For example, for patients at the chronic stage, instead of presenting daily or weekly comparison, the system might deliberately remind patients of their progress compared to a few months ago.

Data: Using vlogs as patient-generated health data. As the current findings demonstrate, vlogs as a video-based social media platform offer abundant opportunities to generate patient data. ***Patient-generated health data (PGHD)***, defined as "health data – including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information – created, recorded, or inferred by or from patients or their caregivers" have received increasing attention in clinical research[19]. As Lupton put it, the activities of patient using technologies to self-monitor their physical states, treatment recovery, and lifestyle, is "not only a technology of the self, but it is also a data practice[18]." On a micro scale, a video contains multi-dimensional forms of information about a patient's life and health states compared with text- or image-only media. They could offer a more holistic picture of patients' functional states "in the moment" (e.g., range of movement, speech tempo, walking speed), living environment (e.g., facilities, physical space), as well as social context (e.g., alone or with others). On a macro scale, video blogs that are posted on social media can easily reach on a global viewership, leading to online discussion and community building.

Therefore, we believe that vlogs as a unique form of PGHD can be used to derive insights for patients and healthcare professionals to make decisions. Patients' personal data that contain features of disease could facilitate the diagnosis and treatment plan. For example, patients' photos might help neurologists define diagnosing and defining the timing

of stroke[15]. Meanwhile, contextual information embedded in videos (e.g., home environment) might also provide vivid presentations for healthcare professionals to infer the association between patient health and their living environment. With the advancing technologies of computer vision, natural language processing, as well as machine learning and artificial intelligence, future technologies may be designed to automatically quantify, analyze patient health, and make recommendations through visual and audio cues.

Inevitably, vlog data also incur privacy concern. As shown in Figure 1 and Figure 2, vlogs are highly visual and usually contain patients' faces and personal lives. Since the vlogs and comments are public, vloggers might require more negotiation of privacy, disclosure, and boundaries to protect their safety and privacy[13]. Similarly, patients who comment and interact with vloggers online might also disclose their disease and health information. How to protect patient data privacy while preserving the utility still require further evaluation.

Service: Using vlogs to provide patient-centered education. Vlogs could also provide patients and healthcare professionals valuable educational materials from the patient perspective, which we refer to as ***patient-centered education.*** Traditionally, patients passively take information and advice from health providers. Online health educational videos are also commonly produced by healthcare professional[8,9]. In this study, however, we found emerging evidence of patient viewers learning from vlogs, as well as healthcare professionals who integrate patients' experience into their professional practices. Such information includes the cause of stroke, diagnosis, treatment, therapies, exercises, and activities of daily living.

As the comments show, educational videos from a patient perspective could better connect to an audience with similar experiences. Viewers who were stroke patients or their caregivers appreciated being inspired by the effort and the progress the vloggers have made. Meanwhile, some videos presented patients' self-practices for their recovery, including self-management tips and exercises they learned from health professionals and self-exploration. Viewers of these clips who also experienced stroke pointed out the educational value of these videos by enabling them to follow the exercises or tips. Some vlogs also served as a platform for the viewers to ask questions and seek peer mentoring. For some viewers, they considered videos from stroke patients more useful than those from professionals. Surprisingly, we found that some videos also provide educational value for healthcare providers and students. Vlogs present live examples, insights, and challenges of stroke patients on managing their diseases outside the clinical setting. Watching the videos helped some viewers who were healthcare professionals make treatment plans congruent with what matters to patients. This is also reflected in the case study of a cystic fibrosis patient vlogger[20]. Therefore, it is promising to create platforms that facilitate patient-centered education with videos from patient perspectives.

Meanwhile, it is necessary to integrate healthcare professionals' perspectives. While recovery tips were generated from patients' personal experience, some of them may lack evidence-based and professional support. Moreover, as vloggers mentioned, stroke patients are highly heterogeneous in their symptoms, recovery, and treatment plans. Some commenters mentioned that the exercises and progress recorded by patients with mild stroke might not be applicable for patients with severe stroke. Exposing patients with examples that are not comparable might lead to misuse of information and an ineffective self-management plan. It could also be valuable to include evidence-based information to increase the credibility and reliability of vlogs for educational purposes. By bridging the patient perspective and the professional assistance, we envision that future patient-centered education services can be designed to 1) supplement vlogs with further information to help patients assess the validity and relevance of information in health videos and 2) supplement videos with clinical evidence to scaffold health education.

Limitations. The vloggers in this study varied greatly in the number and frequency of vlogs, the number of subscribers, quality of videos, as well as degree of social interaction on the videos. They were selected as a convenience sample, which suggests the possibility of bias in the data provided by this cohort. We plan to continue to analyze the factors influencing vlog popularity and viewership. Further, we noticed that a few vloggers might have stopped this practice. An interview study on vloggers could provide more insight on their experiences with vlogs or reasons behind discontinued usage.

Conclusions

We present a study analyzing stroke patients who post video blogs on YouTube. We found that videos become a convenient media for stroke patients to self-journal and connect with others online. Using a combination of narration and demonstration in video blogs, stroke patients present the cause and onset of stroke, treatment and therapies, activities of daily living, as well as their functional states. After viewing the videos, commenters offer encouragement and praise for vloggers' effort, expressed their appreciation for inspiring and educating the viewers, and continue to

ask questions and request information. We suggest that future health systems could integrate patient vlogs to design self-tracking technologies, to generate patient health data, and to offer patient-centered education services.

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